WS5.1 Improving the annual review process – the rainbow project

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Background: The CF Foundation encourages CF centres to undertake local projects with the aim of improving CF Care. In 2012 a retrospective audit of the CF Annual Review (AR) process at Mater Children's Hospital (MCH) was conducted. Whilst the percentage of ARs completed was found to be high, it was recognised that the vast amount of patient information being obtained was being underutilised.
Aims:
a. To increase the AR completion rate.
b. To ensure that 100% of ARs have finalised documentation.
c. To ensure all AR are discussed by the multi-disciplinary team (MDT).
Methods: A new system was developed. A colour-coded spread sheet was used allowing easy identification of the point at which the patient had reached in the AR process; hence termed 'the rainbow project'. Collected information was presented weekly at the CF MDT meeting. A proposed plan for each patient was discussed and specific goals for the following year agreed by the MDT. AR letters were finalised following discussion and reviewed with families when next seen.
Results: A review was undertaken 6-months after commencement and demonstrated successful introduction of the process. 100% of patients undergoing an AR were discussed by the MDT with the identification of specific goals for the following year. Additionally, in all cases an AR letter was sent to both the GP and family.
Conclusion: Improved adherence was seen with the new system. We speculate that refinement of the AR process has led to improvements in CF care delivered at our centre. A further audit is currently underway to assess this.

WS5.2 Travelling abroad with cystic fibrosis (CF): current practice and problems

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Objectives: Patients with CF are increasingly undertaking travel abroad. Recommendations have been published (J Cyst Fibros 2010; 9: 385) but there are limited data on the travel practices of patients and the problems encountered.
Methods: We undertook a structured interview of 100 patients (53 men, age 17–56 years, FEV1 18–128% pred).
Results: 96% had travelled abroad; 84% within the last 5 years with 75% travelling often, to Europe and worldwide. 14% now limit travel for health reasons: 6 awaiting lung transplant, 6 had advanced lung disease with frequent exacerbations and 2 had other problems. Of those travelling recently 18% did not get insured and 23% had insurance not covering CF. Many limited travel to Europe and relied on the Eur Health Insurance Card. 25% were subjected to delays and extra searches at airport security due to medications and nebulizer equipment. Medical certificates helped but there were sometimes language problems. Many patients reduced/stopped physiotherapy, nebulized treatments and nutritional supplements abroad; 44% used nebulized therapies abroad, some having issues around sterilizing equipment and storing DNase. 10 patients experienced a CF-related illness when abroad (7 chest infection, 2 dehydration, 1 pancreatitis), 6 consulted a doctor and 3 had a brief hospital admission; 12 had a non-CF illness abroad (4 sunburn, 4 gastroenteritis, 3 ear infections and 1 fall), and 2 had a brief attendance at a hospital.
Conclusion: Patients with CF travel often and widely. Travel insurance is a key issue. Some patients with advanced disease prudently avoid travel. Serious medical problems are rare in those travelling with the approval of their medical team.

WS5.3 Improving care for adults with end stage cystic fibrosis at Bristol Adult CF Centre (BACFC)

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Objectives: Managing end stage disease in CF remains challenging. Patients experience high symptom burden, protracted disease course and need to consider lung transplant. Most patients consider end of life care but few discuss it with their CF team (Sawicki et al., 2008). Our aim was to improve care of patients with end stage disease through review of previous care.
Methods: Retrospective analysis of deaths from 2007–13 and review of all current patients with end stage disease (FEV1 <30%/considering transplant) was performed.
Results: In the deceased group (n = 17), 94% had end of life discussions. 63% died in hospital, 31% at home, 1 at a hospice. Mean duration from 1st discussion to death was 282 days (range 1–1095 days). 3 deaths were sudden. Mean age at death was 31 yrs, mean FEV_1 24%. 38% of patients accepted psychology support. 4 patients were on lung transplant list, 1 being assessed, 1 post-transplant. Palliative care reviewed 25% patients. Bereavement support was offered to 50% of families. In end stage disease group (n = 18), mean age is 26 yrs, mean FEV1 24%. 3 patients are on lung transplant list, 3 being assessed, 1 post-transplant. 58% have so far discussed end of life care with 32% having a 'do not resuscitate' decision agreed. 82% accepted psychology support.
Over 50% patients suffer >5 symptoms daily; most commonly dyspnoea, pain and secretions. Anxiety (51%) and depression (40%) had a high prevalence. 86% of patients required oxygen and non-invasive ventilation in 40%.
Conclusion: Providing palliative care for CF patients presents unique challenges. To improve care we introduced Palliative care guidelines, annual review changes and increased staff education.

WS5.4 Can registry data be used to examine cystic fibrosis (CF) health service utilisation? Perspectives of the Irish CF Registry

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CF registries provide data that contributes to better management of health resources, evaluation of care services policies and development of care accreditation processes. In this study, we examine patterns in CF service usage, using data from the Irish CF Registry.
A cross-sectional, population based analysis of Irish Registry patients was undertaken, with clinical data abstracted from annual registry records (2008 through 2012). Variables of interest included hospitalisations, respiratory medications and culture samples.
Over the five-year period, the annual frequency of hospitalisations increased from a per-person average of 0.65 to 1.02. An increase was observed in the use of beta-agonists (47.7–65.8%), rhDNase (32.3–45.7%), H2 receptor antagonists/proton-pump inhibitors (28.5–41.2%) and nebulised hypertonic saline (3.1–44.9%) between 2008 and 2012 respectively. The per-person average of pulmonary exacerbations requiring IV antibiotics also increased from 0.9 to 1.3. Conversely, the per-person average of cultured sputum specimens declined from 8.9 to 5.8.
Preliminary analysis of Irish CF Registry data suggests that temporal patterns in service usage at CF centres/clinics may be emerging. Profiling health service usage patterns may be useful for optimising the planning, financing, and delivery of quality care to patients with CF in the future.
Furthermore, CF-related services accessed by patients outside CF centres/clinics is largely undocumented by CF registries. A pilot programme is underway to gather and analyse community prescribing information between 2008 and 2012 to address this gap in knowledge.
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